May 7, 2013

Senator Rick Jones Chair, Michigan Senate Judiciary Committee

RE HB 4382 and 4384

Dear Senator Jones:

I would like to express my concerns with HB 4382 and 4384, which your committee is considering today.

I have been working in the field of medical ethics for over 30 years, writing and speaking on a wide variety of issues. In that time, I have also served as a consultant to various Michigan hospitals, health systems, and health care providers regarding both individual patient cases and policies concerning ethical challenges in medical care.

I can no longer count the number of situations I¹ve encountered in which the needs of a severely or terminally ill incapacitated person have not been met because he or she had a court-appointed guardian who believed he had no legal authority to agree to a DNR order, **or to any other decision** to limit so-called life-prolonging treatment. This has long been a major problem in Michigan, as documented in a poll I conducted 2 years ago among hospital ethics committees in the state. (Available on request)

So you'd think I'd be delighted with these two bills, since they appear to be directly attacking this problem. Indeed, I support the goal of clarifying the authority of guardians over end of life decisions so they can better serve the needs of seriously ill, incapacitated persons in Michigan. Well-intentioned as they are, however, these bills fail to achieve this goal in 4 significant ways.

First, both bills address only the use of cardiopulmonary resuscitation (CPR). But in caring for terminally or severely ill persons, there are many other decisions to be made about starting or stopping a long list of other possible medical interventions beside CPR. Will the bills lead to better care for patients slowly dying on a ventilator? For patients who've stopped eating and drinking as a natural part of the dying process who might be kept alive a little while more by artificial feeding methods?

So serving the interests of incapacitated persons requires that the guardian's authority be broadened beyond the DNR order. Guardians should have the authority to approve a medical recommendation that a medical intervention or service be withheld or withdrawn, because doing so is in the best interest of the ward.

Second, HB 4384's revisions to EPIC as written may grant the guardian too much authority. In order to exercise his authority, 5314.D.ii would require that "THE GUARDIAN CONSULTS DIRECTLY WITH THE WARD'S ATTENDING PHYSICIAN AS TO THE SPECIFIC MEDICAL INDICATIONS THAT WARRANT THE DO-NOT-

RESUSCITATE ORDER." Requiring the guardian to "consult" with the attending physician does not make it clear whether the guardian is authorized to withhold treatment only in accordance with the attending physician's recommendation. This limitation needs to be explicitly made, because in many cases the public guardian has no knowledge of the person or the person's prior values and wishes. Patients, their DPOAHC patient advocates, or their families have a right to act against the physician's recommendation by refusing DNR or other treatment because we have reason to believe they are acting from their knowledge of the patient and her wishes and values. Guardians don't have an adequate ethical or legal foundation for such a right to refuse. unless they happen to be appointed by the patient under a DPOAHC or have other evidence of the patient1s prior wishes or values. Otherwise the guardian should be empowered to act only in accordance with the physician's written opinion that withholding or withdrawing a particular medical intervention is in the patient1s best medical interests. Limiting the guardian's authority in this way in HB 4384 also will make the requirements in EPIC consistent with those in HB 4382's amendments to the DNRPA, where the attending physician has to agree in writing to the medical appropriateness of a DNR order.

Third, there is unfortunately too much evidence that physicians and other able-bodied persons can unwittingly make discriminatory and unwarranted judgments about the quality of life enjoyed by disabled citizens. Giving an open-ended authority to withhold potentially life-prolonging treatments to guardians who have too little knowledge of the individual's wishes or capacities could enable premature and prejudiced decisions about the lives of some disabled citizens. One effective way to reduce if not entirely eliminate this risk is **to limit the guardian's authority to cases of terminal illness**, in which the patient is expected to die within 6 months even with provision of standard treatment.

Fourth, in HB 4384's revisions to EPIC, DNR is defined in a way that effectively limits the guardian's authority to out-of-hospital settings.

HB 4384 defines DNR at 1103.P: "DO-NOT-RESUSCITATE ORDER" MEANS THAT TERM AS DEFINED IN SECTION 2 OF THE MICHIGAN DO-NOT-RESUSCITATE PROCEDURE ACT, 1996 PA 193, MCL 333.1052.

As revised in HB 4382, Section 2 of the DNRPA defines DNR at 2.F: "Do-not-resuscitate order" OR "ORDER" means a document executed UNDER THIS ACT directing that IF AN INDIVIDUAL suffers cessation of both spontaneous respiration and circulation in a setting outside of a hospital resuscitation will not be initiated.

Although the DNR order is what the **DNRPA** is intended to authorize, neither "DNR" nor any other order to forego or withdraw a medical intervention should be defined by reference to the setting in which the order is implemented. There is no ethical or legal justification for giving guardians authority to approve DNR everywhere but the hospital where their wards are admitted.

These concerns could be addressed by simple amendments to these bills that are currently under discussion among a number of organizations and individuals who may also testify today. Although the specifics are yet to be finalized, I am attaching a draft version of those amendments.

Sincerely,

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The opinions expressed here are my own and don't represent the views of the Center for Ethics and Humanities in the Life Sciences, the College of Human Medicine, or Michigan State University.

Recommended Amendments to HB 4382 and 4384

Goal: Revise HB 4382 and 4384 to give guardians the authority to approve medical recommendations to withhold or withdraw non-beneficial care in cases of terminal illness.

Amending HB 4384 (re EPIC)

- 1. Amend Sec. 1103 (P)
 - a. Currently reads "DO-NOT-RESUSCITATE ORDER" MEANS THAT TERM AS DEFINED IN SECTION 2 OF THE MICHIGAN DO-NOT-RESUSCITATE PROCEDURE ACT, 1996 PA 193, MCL 333,1052.
 - b. Revise to read "*'Limitation of non-beneficial medical treatment*' means a plan of medical care recommended by a physician to withhold or withdraw a medical intervention or service because it is not in a persons best medical interest to receive it"
- 2. Amend all subsequent references to "do-not-resuscitate order" to read "limitation of non-beneficial treatment."
- 3. Amend Sec. 5314 (D)(ii)
 - a. Currently reads "THE GUARDIAN CONSULTS DIRECTLY WITH THE WARD'S ATTENDING PHYSICIAN AS TO THE SPECIFIC MEDICAL INDICATIONS THAT WARRANT THE DO-NOT-RESUSCITATE ORDER."
 - b. Revise to read: The guardian consults directly with the ward's attending physician and obtains a written recommendation co-signed by a second physician recommending the limitation of specific medical interventions or services, and certifying that in their best medical judgment
 - i. The recommended limitation of non-beneficial medical treatment would be in the ward's best medical interests.
 - ii. The ward, being terminally ill, would be eligible for hospice care under current standards of medical care.

These amendments to HB 4384 require that HM 4382 be amended as follows:

Amending HB 4382 (re the DNR Procedures Act)

1. Amend Sec 3A (1) to read A GUARDIAN WITH THE POWER TO EXECUTE A DO-NOT-RESUSCITATE ORDER Limitation of non-beneficial medical treatment UNDER SECTION 5314 OF THE ESTATES AND PROTECTED INDIVIDUALS CODE, 1998 PA 386, MCL 700.5314, MAY EXECUTE A DO-NOT-RESUSCITATE ORDER ON BEHALF OF A WARD AFTER COMPLYING WITH SECTION 5314 OF THE ESTATES AND PROTECTED INDIVIDUALS CODE, 1998 PA 386, MCL 700.5314.